

Aspiration, austerity and ableism: to what extent are the 2014 SEND reforms supporting young people with a life-limiting impairment and their families to get the lives they want?

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In England, legislation introduced in 2014 to reform support for children and young people with special educational needs and disability (SEND) from birth to 25 years of age has been described as the biggest change in SEND for 30 years. Support now focuses on improved outcomes for young people with SEND, and aims to be more aspirational and person-centred, with the child and family 'at the heart of the process'. This could be viewed as timely for young people with Duchenne muscular dystrophy (DMD), a genetic life-limiting impairment, who, due to improved care and interventions, are now living longer. The aim of this small-scale qualitative study is to explore whether young people with DMD, their parents and schools feel that these reforms are able to support young people with life-limiting impairments to get the lives they want. Findings suggest that parents and children with DMD welcome the new person-centred philosophy, but are still forced to fight for funding and support in a system of reduced resources. Austerity and its role in the narrative of neo-liberalism is also explored.

Key words: Duchenne muscular dystrophy, SEND reforms, Children and Families Act 2014, life-limiting impairments, austerity

Introduction

In 2012 the European Commission noted that too few children with special educational needs and disability (SEND) were leaving school with qualifications or moving on to employment across Europe (European Commission, 2012). In England, many similar concerns were highlighted in a series of reports between 2009 and 2011: the Lamb Inquiry on parental confidence in SEND (Lamb, 2009) reported tense and broken relationships between parents, schools and local authorities; the Ofsted (2010) report *A Statement is not enough*, among other things, discussed the lack of destinations post-19 years for young people with SEND and their outcomes; and the Green Paper entitled *Support and Aspiration* indicated that young people and families needed to have far more control over the process of identifying and achieving their aspirations and that support should be put in place early and quickly (DfE, 2011). In this context, the introduction of legislation that Edward Timpson, the then Minister for Children and Families, suggested would bring about 'the biggest, most ambitious and most aspirational reforms to Special Educational Needs provision in more than 30 years' could be viewed as long overdue (DfE & Timpson, 2014).

The aim of this article is to explore the extent to which young people who have the life-limiting impairment Duchenne muscular dystrophy (DMD) have found the new SEND legislation helpful in supporting them to achieve the lives they want. DMD is a rare genetic muscle-wasting impairment that affects one in 3,500 male births (Emery & Muntoni, 2003). As it is caused by a fault on the dystrophin gene which is on the X chromosome, it affects predominantly males, who, on average, lose the ability to walk by the age of 12 years, and historically have had a mean life expectancy of 19 years (Bushby et al., 2010). DMD can be viewed as a neuro-developmental rather than simply a physical impairment (Ricotti et al., 2016). Young people are at higher risk of experiencing specific learning difficulties such as dyslexia and attention deficit/hyperactivity disorder (AD/HD), and a higher than average proportion have diagnoses of autism spectrum condition and obsessive compulsive disorder, and experience internalising and externalising behaviours (Hendriksen & Vles, 2008; Hinton et al., 2009; Ricotti et al., 2016).

Like young people with other life-limiting impairments, those with DMD are now living longer due to a range of treatments, such as cardiac management and ventilation, that have enabled some men to live into their 30s and 40s (Eagle et al., 2007; Hastie & Chapman, 2017). Despite longer life

expectancy, continued low expectations have meant that adults with DMD have been referred to as ‘marginalised’ and ‘unanticipated’, with little planning through Transition to Adulthood because nobody expected they would still be alive (Schrans et al., 2013; Rahbek et al., 2005). In interviews with 40 young adults with DMD and their families in the UK between 2007 and 2009, Abbott et al. (2012) reported that the Transition to Adulthood process was problematic for the overwhelming majority, with planning, services and support inadequate and yet to catch up with the improved life expectancy in DMD. Men with DMD who were interviewed were in most cases living at home with their parents, and only one person had experienced paid employment; most experienced very little social contact with people outside their immediate family. The impact of living with DMD negatively affected families, with 80% of the parents meeting the clinical criteria for depression (Abbott et al., 2012). Therefore, young people with DMD would certainly benefit from a SEND system that could help them to have higher aspirations in the context of extended life expectancy, while supporting the physical, emotional and learning needs associated with their impairment.

It could be anticipated that the new Special Educational Needs and Disability Code of Practice, with its focus on and new chapter dedicated to Transition to Adulthood, would eradicate some of the problems that adults with DMD have reported (Abbott et al., 2012). It is now a statutory duty to consult all young people with SEND aged between 14 and 19 years about their future – the sort of education and employment they would like to achieve; where they want to live and the type of housing they want to explore; their community inclusion and friendships; and finally their health care. Young people should not have blanket decisions made about them – they must be listened to (DfE & DoH, 2015). The focus on outcomes such as employment in the SEND reforms has led to a renewed emphasis on initiatives like work experience, apprenticeships and the introduction of supported internships, which are structured study programmes based primarily at a workplace which enable a young person with SEND aged 16 to 24 years to develop the skills needed to obtain a job (DfE, 2017).

As well as gaining employment, having independence in living arrangements has been reported as key to quality of life and choice for disabled people everywhere (Morris, 2006). In Denmark, where state support for disabled people is greater than in the UK, adults with DMD live independently in their own apartments and employ personal assistants. This has been described as ‘dependent independence’ (Dreyer et al., 2010): the

adult with DMD is able to make choices although is dependent on a personal assistant to support him with most day-to-day activities. Support for living independently has become more common in the UK over the last few years as life expectancy has increased (Hastie & Chapman, 2017). In Japan, where there is very limited state support for disabled people and no national health service, adults with DMD still choose to live independently with personal assistants rather than live in much safer sanatoriums because they value choice and independence above safety. This has been referred to as 'self-reliant independency' (Yamaguchi & Suzuki, 2013).

Some question whether the focus on getting work or a place to live is appropriate for young people and adults with chronic conditions. Priestley argues that ideas of 'transition' and 'adulthood' are socially constructed and do not consider variables such as disability, gender or other difference (Priestley, 2003). Research with adults with DMD in Canada has criticised the 'normalised' ideals of adulthood that view employment and residential independence as indicators of success, and put pressure on people to reach some standard that they will struggle to attain (Gibson et al., 2014; Hamdani et al., 2015). Gibson et al. (2014) report an adult with DMD stating during an interview that he would rather spend the little time he has left with family and friends rather than looking for a job. They also argue that those who do manage to gain employment remain marginalised.

Nevertheless, others argue for the rights of disabled young people to gain access to real work opportunities. In her review of Disability Employment Support in the UK, Sayce (2011) argues that being able to work is not only important for income and social status, but also for people's health and ability to develop and keep relationships. Along with others, she reports that disabled 16-year-olds have aspirations to stay in education and find fulfilling careers that are similar to those of their non-disabled classmates (Sayce, 2011; Burchardt, 2005). Similarly, after carrying out interviews with disabled children, Connors and Stalker (2007) reported that the interviewees always talked about their similarities to, rather than their differences from, their non-disabled peers, suggesting that they did not have dissimilar goals or ambitions.

Implementation of the reforms

On the surface, and initially perhaps, the changes in legislation did appear to be 'aspirational reforms': a single Education, Health and Care (EHC) plan from birth to the age of 25 years replaced the Statement of special

needs, to be funded by education, health and social care services, thus removing the lack of accountability that families had complained of; every local authority by law must advertise a 'local offer' of what is available for young people and families in their local area; personal budgets were introduced to provide an element of choice; and a chapter on transition in the Special Educational Needs Code of Practice placed an emphasis on post-19 outcomes and destinations (DfE & DoH, 2015). The legislation stresses the accountability of every teacher in providing high quality first teaching for all children regardless of SEND, and a national report on initial teacher training published the following year highlighted the importance of SEND training for all pre-service teachers (Carter, 2015). Above all, the overriding philosophy of the reforms was that families and young people were now, as the Special Needs and Disability Code of Practice states, 'at the heart of the process' (DfE & DoH, 2015).

Initially, the impact of the new legislation looked promising. An evaluation in areas that were 'Pathfinder' local authorities (those areas that had trialled the reforms from 2011 to 2014), which included 698 families and 31 local authorities, suggested that the new system was addressing many of the limitations of the old one. For example, 84% of parents reported greater satisfaction with the process and reported that plans were achieved in a timely way (DfE, 2015). Similarly, a small-scale project reported that families preferred the new emphasis on person-centred planning (DfE, 2016). Research published by the Department for Education and Ministry of Justice in 2017 indicated that, of 13,000 families contacted, 66% of parents and young people reported being satisfied with the new SEND procedures (DfE & Ministry of Justice, 2017).

However, more recently, complaints from families to the Local Government and Social Care Ombudsman (LGSCO) about EHC plans doubled between 2015/2016 and 2016/2017, and in a report of the first 100 cases, the Ombudsman revealed that many councils were unlikely to meet the legal deadline of April 2018 for transference to EHC plans from the old system of Statements of special educational needs; and those plans that were being created were often not within the 20-week deadline (LGSCO, 2017). In some cases, this meant that children with SEND were unable to start school on time. In just under a third of the 30 local authorities they inspected in 2017/2018, Ofsted and the Care Quality Commission (CQC) reported significant concerns about whether the local area was meeting its duties or securing better outcomes for children and young people with SEND (Ofsted

& CQC, 2017). Some of the other criticisms highlighted in these reports included the lack of co-ordination of services, lack of proper assessment, input of therapy, support from local children and adolescent mental health services (CAMHS) and the lack of young people's voices in the SEND process (LGSCO, 2017; Ofsted & CQC, 2017). As the Ombudsman's report noted:

'we have seen some families having to push, persist, and go well beyond the call of duty just to confirm the type of support they should receive, and to get it provided.'

(LGSCO, 2017, p. 1)

It can be difficult not to view the changes in legislation as a consequence of neo-liberal thinking and cost-cutting. In a critical discourse analysis of the 2014 SEND Code of Practice, Burch (2017) suggests that the new legislation, with its focus on employment and independence, has been developed as a tool of the Government to support their national economic and political demands, rather than to address the unique needs and aspirations of young people with SEND. Norwich (2014) warns of the 'rhetoric' of the new legislation, arguing that in fact very little has changed and that the Children and Families Act does not represent a 'radically new system'. He views the changes as reflecting a wider social policy that is driven by economic austerity policies rather than the needs of young people with SEND. For children and young people with more complex care needs, the roll-out of personalisation in social care with the use of personal budgets has coincided with the global programme of austerity. As Pearson and Ridley (2016) ask with regard to the implementation of the personalisation agenda for social care in Scotland, is this bad timing or was this always part of the plan?

Austerity and the timing of the reforms

Undoubtedly, the SEND reforms were introduced at a time of great financial precarity across Europe. The Great Depression of 2008, caused by the banking crisis, led governments across Europe and the UK to make decisions on strategies for financial savings. Under the guidance of the European Commission and the International Monetary Fund, by 2010 many countries, including the UK, France, Portugal, Spain and the US, launched programmes of austerity, making severe cuts to public services. However, according to Stuckler et al. (2017), austerity was not an inevitable consequence, and those lucky enough to live in countries like Germany or

Denmark which have stronger social protection systems have not experienced the same level of cuts.

Across Europe, austerity has caused untold damage to certain sections of the population, particularly those who depend on state welfare support, and studies have shown high levels of poverty, decreased public health, links between austerity and increased suicide rates, a rise in homelessness, as well as lack of services that have negatively affected those with SEND (Karanikolos et al., 2013; Loopstra et al., 2016).

In the UK, disabled people and those with SEND have been disproportionately affected, and research shows that rather than spreading out the burden, the cuts have been directed at the most severely disabled and have served to increase the divide between the most wealthy and least wealthy postcodes (Duffy, 2013; Beatty & Fothergill, 2016). Research published as early as 2012 reported that 81% of local authorities in England set care eligibility thresholds at 'substantial/ critical only'; over 50% closed a disability support service, and in some areas charges to service users rose by 400% (Wood, 2012). The Independent Living Fund, a national funding body set up in 1988 to provide funding for severely disabled adults to live independently at home, was shut down in 2016. Recently, ideas such as 'warehousing' disabled people have re-emerged, with many disabled adults fearful of being institutionalised because local authorities view this as a cheaper alternative to independent living (Brown, 2017). Perhaps it is little wonder that in 2016 a United Nations inquiry concluded that policies introduced into welfare and social care by the UK Government amounted to 'systematic violations' of the rights of disabled people (UN Committee on the Rights of Persons with Disabilities, 2016).

It is not only disabled people and their families who have struggled under austerity. Savage et al. (2013) speak of a rise of a new class, the 'precariat', who depend on zero hours contracts, live in temporary accommodation and lack permanence and consistency. This group of people may often include those who care for and support disabled children and adults, and whom disabled people need to recruit, train and manage. The ongoing struggle is thus not limited to receiving appropriate budgets to live independently as a disabled person, but also involves recruiting and maintaining consistent care staff (Ferguson, 2007; Sims & Whisker, 2015). The focus on independence and social inclusion in the SEND Reforms could therefore feel unattainable, given the social context in which they have been introduced.

Looking at the experience of children and young people in education specifically, reduced budgets for local authorities have meant a lack of specialist support for young people with SEND in schools and in the local community. This includes trained and experienced staff who can facilitate and conduct EHC planning meetings as well as develop the plans themselves. Schools have seen direct cuts to funding, and according to the Education Policy Unit (2018), the new National Funding Formula does not address the pressures on schools budgets, with around a third of local authority secondary schools currently in deficit.

‘High needs’ funding, which is Government funding allocated to local authorities for children with the most complex types of SEND, has been described as insufficient, particularly now that plans are continuing to the age of 25 years (ASCL, 2018). Indeed, Freedom of Information requests have shown that combined high needs education budgets in England increased from £61 million in 2015/2016 to £195 million in 2017/2018, indicating that local authorities have had to use funding from other areas such as mainstream and early years education to cover the shortfall (Jayanetti & Savage, 2018).

Austerity measures have also been blamed for the large numbers of children with EHC plans who are currently not in educational provision (National Education Union, 2017), and waiting lists for CAMHS show these services are unable to meet growing demands (Children’s Commissioner, 2017). Overall, it is difficult to see how young people with SEND could hope to be aspirational or improve their life outcomes when the very services and resources that could support them to do this are being drastically reduced or removed.

Austerity and neo-liberalism

Austerity is cleverly linked to the ideals of neo-liberalism, whereby families are encouraged to be self-sufficient with minimal input from the state (Goodley, 2011). Neo-liberalism champions the rationality of the market and celebrates the ‘ideal citizen’ who is an ‘economic maximiser’ (Lynch, 2006). This citizen has what Campbell (2001) describes as ‘a particular kind of self and body’ that is ‘perfect and species typical’. Although unattainable to all, this ableist ideal serves to support the binary discourse of ‘us’ and ‘them’ which others have argued is intrinsic to neo-liberalism (Ramilow, 2006; Runswick-Cole, 2014): those who are unable to work are depicted as ‘them’, in contrast to ‘us’, the hardworking, non-disabled people who

contribute to the economy. Goodley et al. (2014) explain that neo-liberalism provides an 'ecosystem for the nourishment of ableism', which they term 'neo-liberal-ableism'. Austerity plays an important role in neo-liberal-ableism, celebrating concepts of individualism, decrying dependency on the state, and helping to normalise low wages, budget cuts and precarity (Bates et al., 2017).

Although DMD is a rare impairment, the number of children with complex and life-limiting impairments is rising. An analysis published in 2012 reported that the true prevalence of children living with a life-limiting condition has increased annually in all areas over the past decade and is now 32:10,000, which is double the previously reported estimates (Fraser et al., 2012). It is therefore hoped that findings and discussion from this small-scale study will highlight some of the key issues relating to changes in SEND support for many children with life-limiting and complex impairments who are looking to local services at a time of austerity to support their aspirations and improved outcomes.

Method and methodology

After gaining ethical approval from the University of East London, information letters were sent to the national charity Action Duchenne, which advertised the project through its newsletters and social media. Six families self-referred to take part in the project, and five schools gave their consent. One school declined to be involved. Pupils varied in age from six years to 17 years. Schools varied from a state-maintained primary (school 1), to Catholic primaries (schools 4 and 5), a specialist secondary school for 11- to 19-year-olds (school 2), and a recent secondary school member of a multi-academy trust (school 5). Table 1 includes demographic information about all participants.

The research question for all participants was exploratory: how, if at all, was the new SEND process supporting the young person and his family to get the lives they wanted? In order to ascertain their views about the SEND reforms, all participants took part in semi-structured interviews. Those involving children and young people used age-appropriate language. All interviews were recorded. All teacher interviews took place in school in a quiet space; all interviews with children and young people took place at school apart from participant 6 who was interviewed at home during a free lesson in his timetable; parent interviews took place at home or in a quiet space chosen by the parent (for example, a coffee shop).

Table 1: Participants

Participants: parent (P), child/young person (C/YP), teaching staff (T)	Age of child/young person	Teacher and school status	Location
P1, C/YP P2, C/YP2, T1	6 years 10 years	N/A SENDCo of maintained primary school	South East Welsh Borders
P3, C/YP3,T2	16 years	Deputy head of SEND specialist academy	West Midlands
P4, C/YP4, T3	9 years	Deputy head and SENDCo of Catholic primary school	North West
P5, C/YP5, T4	11 years	Teaching assistant in Catholic primary school	North West
P6, C/YP6, T5	17 years	Inclusion manager in secondary school within multi-academy trust	East Midlands

Talking to parents and young people themselves was a key aspect of this project. Too often in these times of neo-liberal-ableism, the family of a disabled child is viewed through a lens of tragedy, and regarded as an object of pity. Disabled children themselves are often seen as passive, the object of conversations, rather than as 'social agents and co-constructors of their social worlds' (Brady et al., 2015). Following the principles of disabled children's childhood studies, and the sociology of childhood, in this study steps have been taken to place the voice and experiences of the disabled child or young person and his family at the centre (Curran & Runswick-Cole, 2013; James & Prout, 1997).

Furthermore, as DMD is a life-limiting and life-threatening impairment that can bring with it many challenges, the researcher was keen to discourage participants from focusing solely on difficult aspects of their medical prognosis. The risk of making parents 're-live' difficult times has been highlighted for DMD and other life-limiting impairments (Eakes et al., 1998; Poysky & Kinnett, 2009; Stevens et al., 2010). Similarly, Oliver (1990) has criticised the ways in which some interviews can cause disabled people to feel demoralised and disempowered and serve to reinforce the idea that their difficulties are caused by their own 'personal inadequacies or functional limitations'. Therefore it was important to ensure that participants did not feel like objects of research but rather as experts on their own lives. In order to achieve this, questions used a solution-focused approach, using concepts from solution-focused therapy (De Shazer & Dolan, 2007). Thus, for example, young people, parents and schools were asked to think about their best hopes for the new SEND legislation and how they were currently using it to achieve the lives they/the young person wanted. What did it look like when it was working? This in no way meant that challenges and barriers were not discussed, but it did enable participants to view these barriers from a position of control rather than feel overwhelmed by them. In addition, as the researcher was the parent of an adult with DMD, it was easier to establish rapport and trust with participants who did not view her as an 'outsider' with no understanding of the challenges they faced (Stevens et al., 2010). A small group of adults with DMD offered support through a steering committee to ensure that questions were appropriate and to advise on any omissions.

The data were interrogated for themes, and Braun and Clarke's (2006) six-step approach was used to identify and analyse them: becoming familiar with the data, generating initial codes, finding themes, reviewing them,

naming them and writing the report. The researcher was self-reflexive, returning to the data regularly once the initial themes had been identified. This was particularly important in this case, as the researcher was a parent of an adult with DMD and was keen to ensure she was aware of any preconceived views. Four themes were identified: embracing the new person-centred philosophy and the focus on outcomes; the survival of the 'warrior parent'; lack of knowledge about DMD among professionals; and finally the impact of the programme of cuts or austerity.

Findings

Theme 1: young people and parents embrace the new person-centred philosophy and the focus on outcomes

The first theme supports the positive findings about the EHC system from early users of the new system and the Pathfinder (pilot) evaluations (DfE, 2014, 2015, 2016). All parents and young people reported that they preferred the new person-centred approach associated with the SEND reforms to the old SEND system. Three of the other mothers (3, 4 and 6) had taken part in transition projects or pilots concerning the new legislation and were positive about its philosophy. In particular, all participants reported that the new legislation had offered the opportunity to hear the voice of the young person and to enable them to think about their aspirations. Most children/young people (C/YP) reported that they felt listened to about their plans for the future. C/YP 6 said of the new process, *'I think it's useful to be able to plan what you want to do in the future'*, and others compared this favourably to the previous SEND system in which they were often not invited to either attend their annual special educational needs review meetings or to speak. Parents and teachers appreciated the focus on the young person's views and hopes, and felt that the process was more up to date than focusing on early diagnostic information. As one parent put it:

'he's grown and he's thought yeah I have got a voice and I can speak up for myself. They [school in the EHC meetings] always ask about his aspirations now.'

(P2)

All parents were positive about direct payments and personal budgets, and either were using direct payments already or liked the idea of being able to buy in the support when they needed it.

Furthermore, the emphasis on improved outcomes for the future, in particular with regard to issues such as employment for young people with special educational needs, was seen as an important change. Teacher 2 talked about the change of focus in his special school due to the legislation for post-16 opportunities, and the introduction of new initiatives such as supported internships:

'I would say the Green Paper inspired our head teacher ... we always had this cliff edge when they finished 6th form a lot of students were either going on to college and it was just not working, then they were dropping out and then going on to benefits and their life expectancy and their aspirations were just shot'.

This was confirmed by parents who all talked about their sons' plans for working in the future. It was assumed by parents and young people that getting a job would be part of their future and none of them suggested that not working would be a better option. One said the new focus on employment and work experience was helpful, stating:

'they've [young people with DMD] got to learn that you've got to help yourselves, we're not there all of the time ... that's what we're trying to tell them, I hope they've listened'.

(P2)

On the other hand, feedback from teachers about the aspirational and person-centred aspect of the legislation was more mixed. Two of the teachers who were special educational needs and disability coordinators (SENDCos) and held senior management positions were very supportive of the changes, with one explaining that she had only just completed her SENDCo training and had never experienced any difference. Staff from two of the schools felt the ideas were good but were still reticent to believe that without any extra funding major changes would happen. One member of staff stated that they *'could not see any difference'* from the old system (T4). One teacher felt that a student in her school who had severe dyslexia as well as DMD had too many barriers to learning for her to feel aspirational for his future. When he suggested he would like to be a car designer in the future, she felt that this would not be possible because of the multiple barriers in his way: *'If it was just dyslexia then it would be different'.*

A key finding worth noting was the disparity between this first theme, which was predominantly positive – young people and families really

valuing being listened to and being central to the planning process – and the other themes, which at times appeared to contradict this finding. In other words, there appeared to be a marked difference between the philosophy of the new legislation and its implementation.

Theme 2: the continuation of the 'warrior parent'

In his 2009 report on parental confidence in special educational needs, Lamb (2009) referred to the emergence of 'warrior parents' who were placed in a situation of conflict with their child's school over required support and intervention. The new emphasis in the legislation on placing the parents and child 'at the heart of the process' (DfE & DoH, 2015) was intended to end these battles. However, it would appear from these interviews that the struggles between families, schools and local authorities are ongoing.

For example, teacher 5, when asked about how the SEND reforms were supporting a young man with DMD, replied:

'the drive of the mother has overridden any process if you like, so any success that the young person's had, you know, achieving things or gaining things, has not been through going through the process ... the success is wholly driven by the mother's tenacity to make it happen.'

Teacher 5 was very clear that the process '*per se*' was not what had enabled the young person to do well at school and to access the support that he needed. He cited other young people with SEND at his school who had not been able to do this, and was adamant that the input of his mother was the defining feature of the young person's success.

Parents reported battles with school, and those who had older boys felt that they had to fight for social care, even though their boys were not ambulant and therefore should qualify for social care support to help with personal care (for example, getting up and going to bed) and for short breaks funding (for example, funding to enable a young person to go out independently with an assistant). Parents also talked about a lack of support from local health authorities who were difficult to get hold of, and did not attend meetings or contribute to the EHC process without prompting.

Half of the parents were well informed about the SEND reforms, having benefited from a range of training and support. One mother had been part of the Pathfinders pilot project for SEND reforms from 2011 to 2014, and another

had been part of a charity-led Transition to Adulthood project that had given training to parents about the new legislation (Takin' Charge, Action Duchenne). Another parent was involved with her local Parent Forum group (a parent-led organisation existing within local authorities) and had attended many of the free training sessions that had been offered by local authorities about the new SEND legislation. Although she reported often disagreeing with her son's school over issues regarding his support, she repeated several times *'it's working with, not working against school'*, and was keen to focus on supporting her child's ambitions rather than being involved in conflict. However, in practice, school staff reported that her *'working with'* them was often confrontational, and sometimes felt that her expectations were not realistic, in terms of what her child could accomplish with the resources available.

Theme 3: Lack of professional knowledge and understanding of both DMD and the new SEND system

Linked to the theme of the 'warrior parent' is the lack of awareness and training that professionals have with regard to both DMD and the new SEND system. Parent 1 talked about her relationship with school, saying: *'they're asking the parents for advice. And we're looking to them for advice'*. Specific learning difficulties such as dyslexia are a common co-occurrence in DMD, yet parents reported having to fight for assessment and diagnosis even though their sons presented with literacy difficulties. One mother, whose son was almost 10 years old and was still unable to read fluently, talked about her struggle to understand why:

'He doesn't fit any categories and that's really hard but, I wonder, you see, I always wonder now he's hit 9 [years] whether he is dyslexic on top of everything else but I don't know how you go about testing that or whether it's just the learning.'

Presumably his school would have been aware of the high risk of co-occurrence of such impairments, yet the parent was still *'wondering'* and her emphasis of the phrase *'on top of everything else'* indicates that she felt she was making too much of a fuss in looking for extra labels for her son.

As well as a lack of knowledge of DMD, parents also reported that schools were not aware of changes that the new legislation had introduced. For example, one parent described a SEND review meeting she had attended at school where there had been a discussion about her son applying to university the following year:

'So basically when we had the review of the plan last year nobody in that room except for me knew that plan didn't carry on to university. So they're all sitting there going "Really?" And I said: "No!"'

Similarly, the lack of knowledge from those working in social services was mentioned by both mothers 3 and 6, whose sons were both non-ambulant and who depended on direct payments from social care to fund domiciliary care and short breaks. According to the Children and Families Act (2014), the new EHC plans bring services together to jointly support the outcomes that each young person and their family have identified. Parent 3 described a home visit from a social worker who met her son who had been non-ambulant for seven years:

'The woman that came [from social services] she was like, reading off an iPad and she kept asking B the same question but in a different scenario of how far he can walk, and can you get out of your chair? Then B lost his rag.'

Again, due to the rarity of DMD, professionals are often unaware of its implications for physical health. Most young people will attend a tertiary centre – for example, Great Ormond Street Hospital, if they are living in North London – where they have bi-annual meetings with a neuromuscular consultant and physiotherapist; in addition they receive local health input from their local community care-giver, which can involve appointments with a community paediatrician, a physiotherapist, an occupational therapist and sometimes local CAMHS. Lack of knowledge of local professionals about a rare condition as well as poor lines of communication have been highlighted as problematic (Abbott & Selby, 2017).

Such lack of understanding is illustrated in the case of C/YP 2, whose mother reported on intervention from the local physiotherapist who advised school on her son's toileting needs. Instead of using a bottle to pass urine, as is standard advice for young people with DMD once they are no longer able to stand independently (Abbot & Selby, 2017), staff were advised that due to health and safety concerns the child was to be hoisted onto the toilet at certain intervals throughout the day, even when he had not expressed the need to use it:

'And then he used to kick off because he was being hoisted to the toilet when he didn't want to go ... because one of the TAs [teaching assistants] refused to use that bottle ... and the busybody physio got involved and said that health and safety was to be used when he goes to the toilet because they thought he was going to fall out of his chair when he leans forward'.

(P2)

However, it was not only parents who reported frustration with this lack of understanding. Professionals also reported that they were often left to get on with things, with no specialist support. Teacher 1 reported that as a SENCo in a mainstream school she often felt isolated and lacked the opportunity to meet other teachers of children with rare conditions. In addition, very little training was available for rare impairments.

Theme 4: the role of austerity

Austerity interlinks and underlies earlier themes. The programme of austerity has introduced and justified cuts to many local services, including social care and education services, and anxiety regarding funding emanated from all conversations with parents, teachers and older boys. Parent 6 explained that her son's secondary school included many young people with EHC plans in comparison with other schools in the area. It had become a multi-academy trust and had cut the role of SENCo in order to save money:

'They were looking at resources within the school and they decided that they could deliver SEN provision differently and differently meant getting rid of that person and basically using a SENCo who is in a different school 10 miles down the road who has limited experience of SEN.'

(P6)

This was confirmed by teacher 5, who said:

'when there's a school like us with 14 or 15 EHCPs there's an enormous job to keep them all moving forward ... I'm an Inclusion manager, we're now part of an Academy Trust so we don't have a SENCo in school any more, we have a SENCo across two schools.'

The ongoing restructuring and cutbacks to local authorities have had a major impact on the SEND process in schools, not only in the structure of schools but also in eliminating the roles of experienced professionals who in the past may have provided support and training to teachers. This is illustrated by teacher 2, who said of his local authority:

'The problem is when the cuts came in and they made the decision for redundancies or to move people to different departments, it's not just the people, it's the skill set that was lost. So even when people are brought back on board it's the training – it's getting people up to the required level.'

In England, personal health budgets have been offered to young people and adults living with complex health needs alongside social care support through National Health Service Continuing Care funding. The threshold for this funding is high, and offered according to severity of health need. None of the participants in this study were told they qualified for this funding except C/YP 6. However, just before the interview with the researcher, C/YP 6's personal health budget was stopped due to financial constraints on the local authority. As parent 6 explained, this 'top-up' to funding and resources could mean avoiding a much more expensive future health crisis that could result in a young person being hospitalised.

'For goodness sake ... How ill do you have to be?' she demanded.

The cuts have led families in this project to view the future as precarious. As parent 3 said:

'we've got to think that much quicker now, like they might not need it til next year but then I'm thinking, well we'd better start the process'.

This also affected young people's choices about where they went to university, as the chances of support breaking down were viewed as high. C/YP 6 had achieved very good results in his GCSEs, and for most young people this would mean the choice of any university in the UK. However, his plans for the future were being made with regard to the possibility that funding or support may not be available when needed:

'I think I'd prefer that [i.e. going to a university not too far from home], then if I get any problems then I'm close enough to home for someone to help'.

Discussion

The findings from this small-scale study have shown a mixed response to the SEND reforms from those affected by life-limiting impairments and their families and schools. The importance of focusing on improved outcomes and the voice of young people with life-limiting impairments cannot be underestimated. With reports of such poor outcomes and social isolation of adults with DMD in the past, the chance to be in a workplace and have a social life is a step forward (Abbot et al., 2012). No young person or parent suggested that they could not have serious plans for the future because of

their debilitating condition; in fact having a job and thinking about living arrangements seemed to be very important to them and something to be celebrated. Parents agreed, but also shared their ongoing experiences of battling for adequate support in order to achieve this. Therefore, although others have warned about the pressures of normalising the lives of young people with DMD and unfairly placing expectations on them for employment and residential independence, the young people and their families in this study themselves viewed these as indicators of positive aspiration and success (Gibson et al., 2014; Hamdani et al., 2015). Furthermore, parents and boys tended to view them as rights they needed to fight for, so that boys with DMD had the same opportunities as their peers.

In their analysis of the lives of people with learning difficulties during the time of the Coalition Government in England between 2010 and 2015, Runswick-Cole and Goodley (2015) utilise Berlant's theory of 'cruel optimism'. This theory suggests that despite deteriorating social and economic conditions, people remain attached to 'clusters of promises' even when these are in fact injurious to them (Berlant, 2012). Between 2010 and 2015, David Cameron's 'Big Society' ideology promised citizenship and employment to people with learning difficulties which often remained 'tantalizingly out of reach', thus raising people's hopes for a fairer society which in fact could not be realised (Runswick-Cole & Goodley, 2015). In some respects, Berlant's ideas could equally be applied to the SEND reforms in England: the reforms espoused high aspirations and a focus on post-19 employment and independent living at a time when a brutal programme of austerity has meant that support and resources to reach these goals are minimal.

Indeed, it is not possible to explore the impact of the new educational and social care legislation since 2014 without regard to the role of austerity. Face-to-face services, layers of trained professionals, as well as access to individual budgets and training have been removed over the past eight years, all of which have affected the lives of people with SEND, and particularly those with complex impairments like DMD (Wood, 2012). Personal budgets and direct payments, although they support the idea of choice and control, have enabled some services to disappear and costs to be cut.

Media narratives of austerity and 'the need to tighten our belts' have helped to enable these cuts: reports of disabled people as 'skivers', as opposed to hard-working 'strivers', have been prevalent, and research has shown the rise of disability hate crime (Bates et al., 2017; Burch, 2018). Focus has been

directed away from tax avoidance and fraud, even though the latter has been a substantially larger problem than, for example, benefit fraud (Duffy, 2013), in an environment of 'compulsory able-bodiedness' (McRuer, 2013). In this project, precarity has tended to trump aspiration in families' and young people's decision-making, indicating a clear lack of confidence that resources would remain in place.

Those young people, families and schools who have had the opportunity to learn about the legislation and use it to fight for resources have managed, to a certain extent, to disrupt the challenges caused by austerity measures. Through using the new focus on improved outcomes, they have, in some measure, been able to achieve support for university and opportunities for internships and work experience, as well as highlighting the need for appropriate health and social care support in their plans. By drawing on the 'aspirational' spirit and language of the reforms, families and schools have succeeding in using the law itself, as other campaigners have done in other fields, to achieve what Thompson (1975) referred to as 'an unqualified human good', indicating perhaps that it is not the legislation itself that is the problem but the context and time in which it has been introduced. The promotion and achievement of raised aspirations for disabled young people in times of neo-liberal-ableism could be seen as both contradictory and novel, particularly during a period when austerity has normalised low wages, precarity and a lack of aspiration.

This suggests the importance of advocacy training and signposting for families and those working in education, health and care services in how to navigate the SEND system, and in particular how to support young people with life-limiting impairments to do so. It also indicates that young people with life-limiting impairments have aspirations that are not unlike those of their non-disabled peers, as others have noted (Sayce, 2011). Furthermore, it confirms the need for opportunities to share success stories, where young people with complex impairments and their families have negotiated care packages, organised support for university, and achieved successful collaborative working with school and college. In the absence of experienced local authority professionals, this could be implemented by user-led groups such as parent forums and schools which are seeking to share best practice, or through less formal local networks. In the face of what may seem like enormous bureaucratic barriers, being able to share what works can be powerful and effective for both families and professionals, particularly in the context of DMD, where expectations and aspirations have continued to be very low

due to its serious prognosis. The person-centred planning process, although deemed overwhelmingly positive by families in this study, is only as good as the resources available, and there is a risk of it becoming meaningless if lack of funding denies young people the ability to achieve the outcomes co-produced on their plans. Therefore, understanding how the law can support children with SEND is key, and parents should be made aware of national advocacy and legal organisations.

This is a very small-scale study of families who self-referred, and it is therefore difficult to generalise the findings to the DMD population as a whole. However, uniquely, it does throw light on how the SEND reforms are currently being implemented across England, and on the barriers that can still prevent young people with life-limiting impairments from getting the life they want, at a time when their life expectancy has increased. It is a significant piece of research, as it shares the voices and concerns of young people with life-limiting impairments and their families and schools, who are a growing group within SEND (Fraser et al., 2012). In the current context of improved life expectancy, it is crucial that not only are young people, families and professionals supported to have higher aspirations for young people with DMD, but that these aspirations can be realised with the appropriate resources and funding.

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